

The Honorable Marvin L. Abney
Chairman, Committee on Finance
Rhode Island House of Representatives
82 Smith Street, Hearing Room 35
Providence, RI 02903

July 30, 2020

Include House Bill No. 7924, Support Funding for Medicaid Home Care in SFY21 Article 14

Dear Chairman Abney and members of the committee,

My name is Zack. I am a resident of Warwick and a constituent of Representative Joseph M. McNamara and Senate Majority Leader Michael McCaffrey. For the past few years, my mom came here to advocate for home care nurses to get an increase because they had gone years without one. She knew that my Duchenne's Muscular Dystrophy would continue to progress, and I would eventually need the assistance of nurses to care for me at my home.

Well, I don't think she thought it would happen this fast - but that day came last year - after 87 days of being hospitalized after getting the flu, and a cellulitis infection that resulted in complications that led to me having to get a tracheostomy and use a ventilator to help me breathe. I also needed a Peg tube placed to provide a safe way for me to eat. Before I could come back home, my doctor had to say it was OK and we needed to have nurses lined up to care for me at my house, and both my parents had to receive training to care for me. I am lucky enough that my mom is a nurse and was already familiar with my care, but my dad needed training in the trach and the ventilator as well as the feeding tube.



What would you choose – help keep me safe at home, or make \$10/hr more an hour in a hospital?

I now need nurses with me 24 hours a day. But these nurses cannot be just any nurse. They need to be able to suction my trach, maintain my airway, operate the ventilator that's keeping me alive and most importantly - **they need to know what to do if ANYTHING goes wrong.** They also need to be able to use my cough assist machine with suction so that I can keep my airway as clear as possible. Because of this, they need specific training or prior experience before taking care of me - similar to the nurses who cared for me while I was in the ICU down the street. Except those nurses down the street did not know how to use my cough assist machine and with the exception of the alarms on my ventilator they needed to notify the respiratory therapist to trouble shoot those things or to provide care using the cough assist machine.

It's TRUE that they only need to care for ME at my house, as opposed to multiple patients on the floor of a facility - but with me, they need to know and DO it all. **There is no respiratory therapist, or CNA to come in and help... it's just them.**

It hasn't been easy to get these types nurses to fill all the hours I need. They have the opportunity to make over \$10/hour more in a hospital or skilled nursing facility. **But I need these nurses to work with me - so I can stay at home!** Support H5621 to increase Medicaid reimbursement rates for high acuity home care nursing.

Please consider including the language within House Oversight Committee Chairwoman Patricia Serpa's House Bill No. 7924 in Article 14, Medical Assistance of the 2021 state budget to provide for much-needed financial support and relief to home care providers and hospice providers delivering care to Rhode Islanders like me. In addition, we are seeking a 10% rate increase to incentivize more nurses to pursue enhanced training and skills to deliver care to our highest acuity patients that are difficult to staff and cause frequent hospitalizations charged to the Medicaid Program because of instability in staffing these cases.

Thank you,

Zachary Quinn

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